# Patient Experience
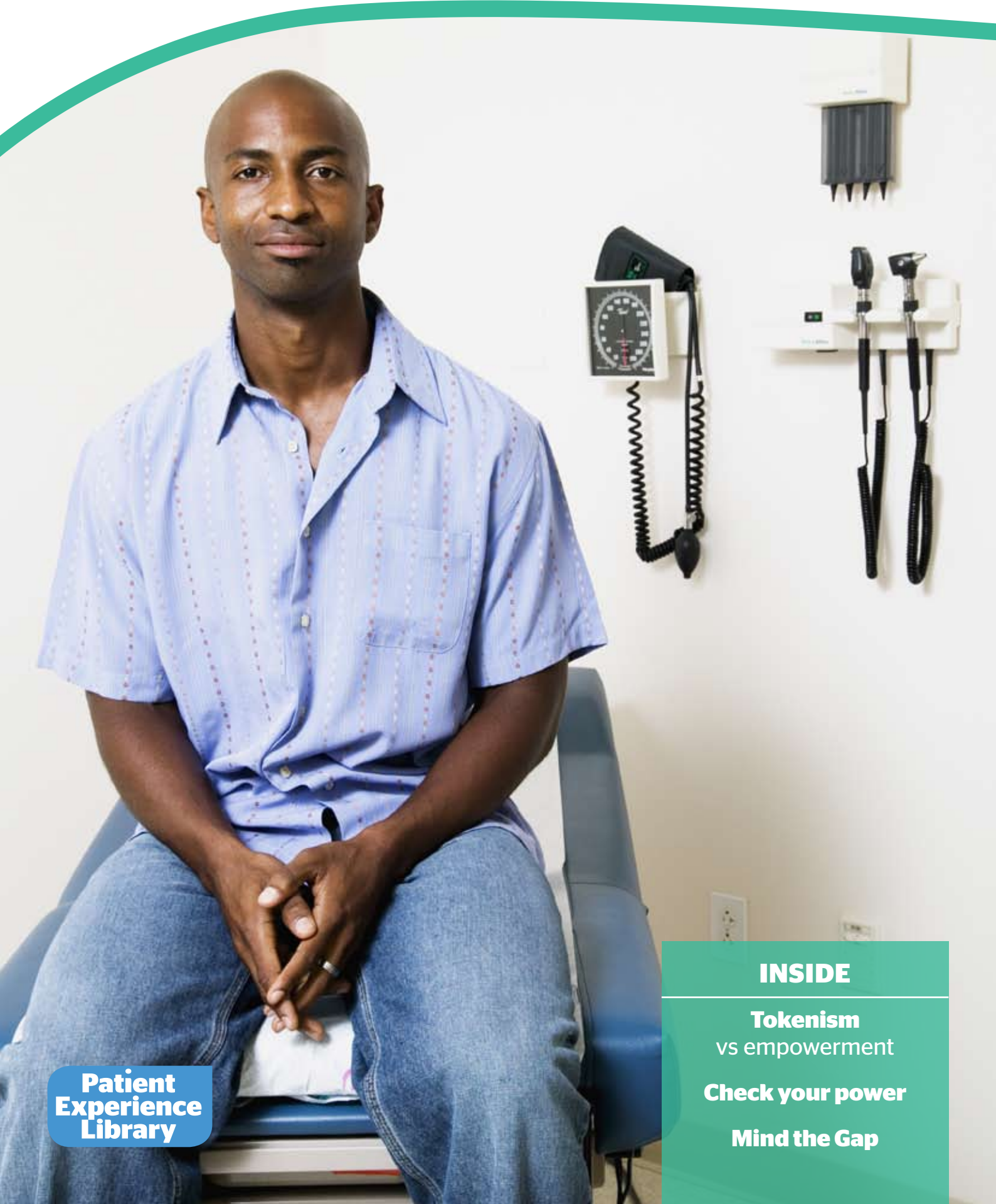
### and patient/public involvement in health and care services

Spring 2018

## INSIDE

**Tokenism** vs empowerment

**Check your power**

**Mind the Gap**

## Editorial

Much of the discussion about patient experience centres on kindness and compassion. Sometimes, the talk is about dignity and respect. But how often do we think about the dynamics of power?

When the focus shifts from patient experience to patient and public involvement, we need to be especially conscious of the power balance between professionals and people who are sometimes described as "lay representatives". How are people invited to engage, and on what terms? On whose territory do meetings take place? Does professional expertise carry more weight than lived experience?

In this edition, we have two comment pieces that address these issues – raising questions, and offering pointers to good practice. Our third contributor describes her encounters with a health system that seems disjointed, unresponsive, even disrespectful. This creates another kind of power imbalance – one that makes a nonsense of aspirational statements in strategy documents.

Patient experience is intimately linked with staff experience. On page 6 you can see three consecutive reports showing that the way healthcare staff are treated directly affects the way that patients are treated. As the NHS finalises its *workforce strategy*, this is vital evidence that must be taken into account.

As we head into April, don't forget *Experience of Care Week*! Details are on page 15.

We're always keen to hear from our readers, so if you know of a stand-out report that we should be featuring, or if you want to submit a comment piece, get in touch!

*Miles*

Miles Sibley, Editor

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## Facts and figures

### New documents Jan-Mar '18
### 1,694

During January – March 2018, we added 1,694 documents to the Patient Experience Library.

Most of these were CQC inspection reports. We collect these because the "Caring" domain in particular can shed light on patient experience.

Around 1,370 came from health charities, think tanks and other government bodies, with around 320 coming from the local Healthwatch network.

Subscribers to the Patient Experience Library can view all of these, and search through over 40,000 documents on patient experience and patent/public involvement by logging in from the *Welcome Page* of our website. For details of how to subscribe, *click here*.

# From tokenism to empowerment

*Josephine Ocloo, Health Foundation Improvement Science Fellow, King's College London*

I first got into "patient involvement" as a grieving mother who had lost a child, my 17-year old daughter, who died as a result of a failure to manage her heart condition. I was subsequently unable to get transparent answers on why these failures occurred. This led to my getting involved with patient safety, both as a campaigner seeking justice for my daughter, but also as a patient activist wanting to change the system and make it safer.

I gradually became involved in all aspects of patient safety – chairing committees and undertaking a PhD which looked at patient safety incidents from the standpoint of those directly affected. I am currently a member of the Learning from Deaths Partnership Board, set up by the Secretary of State for Health in the wake of the Southern Health failings, as well conducting research at King's College London, in the Centre for Implementation Science.

What I bring to all of this – as well as my personal experience – is learning from my professional background in social science. I have always been passionate about creating a society that is based upon social equality, non-discrimination and justice.

Over the years, I have seen projects where patient/public involvement (PPI) has been tokenistic, lacking in inclusivity, and ill thought through in terms of the objectives of the work. At the heart of these problems is the question of whether we take a rights-based or a managerial approach to PPI.

Disenfranchised groups, including black, disabled, mental health, lesbian and gay, and women's groups, can be seen as providing collective challenges to poor care, discriminatory/paternalistic services, and medical policy and belief systems. Campaigns from patients who have been harmed, and their relatives, are another example of rights-based challenges to paternalistic healthcare.

Current models of patient/public involvement (PPI) however, are often rooted in a mechanistic and professionally dominated approach. This narrow "managerialist" or "consumerist" model has its roots in market research and "improving the product". It mainly draws upon data collection and consultation and the reporting of patient survey results at board meetings.

This contrasts with a rights-based approach, which emphasises the direct involvement and empowerment of service users, and broader democratisation at a community level. Such an approach recognises the systemic nature of health inequities and focuses on the need for change within social systems as well as within individuals and services.

Power imbalances in PPI can be reinforced by the question of who to involve. For example, patient representatives are less commonly drawn from black and minority ethnic (BME) groups, yet in the UK it is acknowledged that BME populations experience poorer health and barriers to accessing certain services.

Narrow PPI selection processes mean that those with most to gain are most excluded from healthcare decision making. This restricts the pool of ideas for improvement and limits the opportunity to break cycles of suboptimal care and services.

To move beyond current PPI approaches, we need to address imbalances of power between patients, public and healthcare professionals. We need better evaluation, to understand the effectiveness of PPI methods, and how inclusive they are. And ultimately, we need better training of staff, within organisational contexts where partnership working with a diversity of patients and public is clear, embedded and normal.

*Further reading: **From tokenism to empowerment: progressing patient and public involvement in healthcare improvement.** (BMJ Quality and Safety)*

# Check your power

*Bella Starling PhD, Director of Public Programmes & Wellcome Trust Engagement Fellow, Manchester University NHS Trust & NIHR Manchester Biomedical Research Centre*

Diversity and inclusion is the name of the game at the moment – in both public involvement and engagement spheres. And rightly so: "A diverse and inclusive public involvement community is essential if research is relevant to population needs and provides better health outcomes for all." (NIHR Going the Extra Mile 2015). As a Wellcome Trust Engagement Fellow, I am exploring how public engagement with research can act as a catalyst for social change through a 'learning by doing' approach. So I have been reflecting on my experiences and mentally composing my Top Ten Tips for researchers and practitioners:

**1. Check your power.** Engagement and involvement operate in a context of imbalanced power relationships. Even more so if your aim is to work with vulnerable, marginalised groups or those who might not currently engage. My mantra? Do what you can to understand the politics of power, and your role within that context. Clarify, question, challenge the ethics of engagement.

**2. Listen and seek agreement.** Dialogue simply does not happen without active listening. We have all experienced the situation where people listen, but carry on regardless. Listen carefully. Then act on what you have heard.

**3. Consider the politics of place.** Where you engage needs careful consideration. Some environments can be daunting, territorial, sometimes physically inaccessible and expressions of power dynamics (asking someone to 'come to you' being an exertion of authority). In the complex health sphere, place-based approaches can focus on the social and physical environments of communities rather than on the problems faced by individuals. Place-based approaches are bottom-up and asset-based, enabling communities to participate, lead and own activities, challenging the orthodoxy of 'one size fits all' engagement.

**4. Get from A to B, perhaps via Z.** Your engagement objectives may be clearly defined, but be prepared not to start where you think is the beginning. Be prepared to have some (perhaps uncomfortable) discussions about the weather, poverty, race, discrimination. Take the time to find the common ground and then move forwards.

**5. Collaborate.** A rich plethora of creative, community, cultural, charitable, civil society and other organisations have huge knowledge and expertise in engagement. Some specialise in working with particular groups. Invest in partnerships. Creative methodologies can nurture genuine expression, subvert power and catalyse discussion.

**6. Invest in people, Part 1:** Understand the people you want to engage with – their hopes, fears, likes, dislikes and why they might not readily get involved in health. Use tools like the British Science Association's Mosaic and Audience Spectrum research and the Arts Council's Audience Finder. Take the time to invest in relationships with people and communities. Avoid a quick divorce after you've got engaged.

**7. Invest in People, Part 2:** Public engagement practitioners, leads and facilitators. Invest in diversity and inclusion, and unconscious bias training for all who lead engagement. Seek out and support staff from diverse backgrounds. Avoid the disincentive of short-term contracts for public involvement posts or 'add-on' responsibilities to existing posts. Think creatively about where your talent could come from next.

**8. Evidence, evaluate, reflect.** Theory of Change approaches can work well here: as much for evaluation as for strategic planning and stakeholder engagement.

**9. Act small, think big.** It can be daunting to change the world but a small change can make a big difference. That transformation in confidence, learning and skills that you have nurtured through your engagement, those more diverse voices, amplified in strength and number can lead to further agency of change.

**10. Be values based, socially innovate.** The risk with Diversity and Inclusion as an agenda for public involvement is that it becomes (yet another) box-ticking exercise. Working within a values-driven framework may help, as could including principles of social innovation in our work.

Bella is a member of NIHR *INVOLVE's* Working Group on Diversity and Inclusion. The Group is working with public contributors and researchers to adapt the above principles into national guidance for researchers.

# Mind the gap

*Dr Charlotte Augst, Richmond Group Partnership Director*

In my work for the Richmond Group of Charities, I am part of many conversations about how health and care need to change, about transformation, sustainability, accountability, and so on.

At the same time, my husband is seriously ill. So I bump into a gap between those professional conversations, and what can only be described as the weeds of health and care: disjointed, clunky, often unresponsive, and at times even disrespectful.

Two pictures illustrate this gap – both generated in the same week of my life.

First, a so-called 'placemat' showing NHS England's vision for the future of IT in the NHS.



I can't tell whether it's a list of "things we like" (integrated care plans, decision support) or "things we will do" (apps library, eprescribing). Either way, I am glad the NHS aspires to a 'single source of truth' and 'frictionless performance management'.

Now my second picture.



This is a map of where I live with my husband David, and our two children, Hannah and Ben. It shows the phone calls and journeys I had to make during the course of one afternoon and evening, when David had run out of one of his painkillers, and our regular pharmacy was closed.

So this is me calling the hospice for help, this is me talking to our GP, who had prescribed the medicine, this is me talking to the pharmacy who say that the prescription isn't written in a way that allows them to dispense the drug, this is me calling the hospice for help, this is the hospice calling the pharmacy, then me, then me talking to an out-of-hours GP, twice, who has no access to David's care record, but who then says they can prescribe a small amount of this drug, but they can't fax the script over to the pharmacy, I have to drive over and pick it up, this is me driving to East Dulwich, this is me driving to the late opening pharmacy, and so on.

One source of truth? Frictionless performance management? There is me driving through the night to take a paper script for 8 tablets from one local NHS service to another, David having the shakes, and the children getting smaller and smaller, and paler and paler and more and more anxious about whether their mum is going to cry or scream, or both.

So how are we to think about the gap between what is, and what we think will be? Health policy professionals seem to approach this gap with wishful thinking. "Digital will free up capacity." "Stronger communities will take more responsibility for health." "Increased resilience and self care will reduce demand." Touch wood. God willing. Inshallah.

A real plan for the future should start with my experience that dark night – and with the many, many experiences like it. A plan that was minding the gap would not then look like our place mat. It would see all those professionals 'doing their job' that night as a team and would challenge and support this team to sort it out. A strategy that is silent about faxes, but eulogises about 'machine learning and artificial intelligence' is not a strategy, but science fiction.

Let us mind this gap. Let us care about it. Let us only agree a vision for the future, a forward view, that starts from where we are now and recognisably addresses the issues of the present. Let us describe the next plausible step we need to take, then the next one after that.

And before we fantasise about machine learning and artificial intelligence, let us make full use of their human equivalents.

RECENT REPORTS

Here, we review our top picks of studies and surveys from the last three months. For full attributions, and copies of the original documents, click on the report pictures. Do you know of a stand-out report that we should be featuring? Contact us! info@patientlibrary.net

# Care for staff equals care for patients

## Important learning as the NHS workforce strategy is finalised

A series of reports in the last few months adds to the growing evidence that good patient experience depends on good staff experience.

First up is a study published in BMJ, showing that *"when nurses have high patient loads... necessary nursing care can be missed because of lack of time"*. That may come as no surprise. Intriguingly, though, the study presents clear evidence that while some clinical care may suffer, what really gets hit is the kind of person-centred care that is meant to be the bedrock of good patient experience.
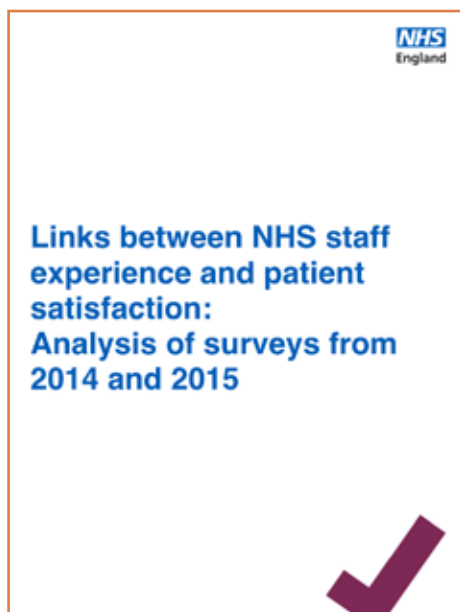
7% of nurses reported that they lacked time to complete necessary pain management, and 11% missed treatments and procedures. But a staggering 52% reported lacking the time to educate patients and their families. Even more – two out of three (65%) – were unable to comfort or talk with their patients.

Another report, from the Kings Fund and Picker Institute, confirms links between workforce pressures and patient experience. They found that on busy wards with high bed occupancy, patient feedback was more negative, particularly in respect of getting comprehensible answers from nurses; and timeliness of response to call buttons. Conversely, patients at trusts with more nurses per bed reported a more positive experience.

The third report takes evidence from NHS staff experience surveys and considers the extent to which staff experience (good or bad) can be a predictor of good or bad patient experience. It found that *"there are some clear and strong associations between staff experience and how satisfied patients are"*.

As with the other reports, workload was important. *"When the pressure is higher, and when staff are less satisfied with the resources and support available, patients clearly notice and have a less satisfactory experience."*

As the NHS and Public Health England finalise the *workforce strategy*, this series of reports presents vital evidence that must be taken into account. They show that in an NHS that aims to be person centred, the way staff are treated directly affects the way that patients are treated.

Optimizing patient and public involvement (PPI): Identifying its "essential" and "desirable" principles using a systematic review and modified Delphi methodology

# Defining patient/public involvement. Should we even try?

## Principles for PPI may be better than rigid definitions.

Patient and public involvement (PPI) can, at times, look like motherhood and apple pie. We can all agree that it is, by and large, a Good Thing.

Agreeing what we mean by PPI, however, can be harder. A recent paper entitled *Zombies and Unicorns* stated that *"there is a lack of consensus about what effective PPI in research processes might look like and... little conclusive evidence about the best (or worst) ways to invoke PPI in research design, research practice, or research commissioning"*.

This paper agrees, pointing to "*a lack of a common language to share PPI practice... the term PPI is not universal in its application or definition*".
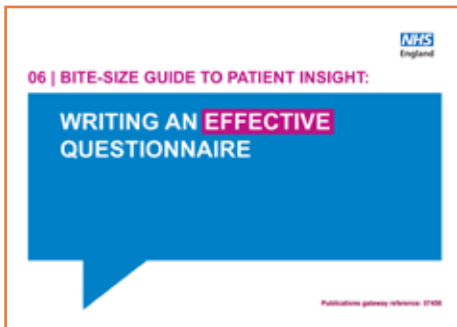
In spite of this, attempts to nail down a definition of PPI may not be helpful. They can lead to *"semantic intricacies"* and *"circular debates held primarily amongst academics"*.

But if we cannot agree a definition of patient and public involvement, how can we aim for consistently good practice? For the authors of this paper, the answer is to aim instead for a basic set of principles – clear enough to be commonly understood, but flexible enough to be applied across different PPI settings.

The paper goes into some detail about the research method, but the important outcome is a set of "essential" and "desirable" PPI principles, assembled from the viewpoints of both patients and professionals.

Equally important is that *"the principles suggested provide quality guidelines for best practice, not prescriptive rules. The proposal of a "one size fits all" approach to PPI would be inappropriate, as no single PPI initiative will work for all situations, individuals or agendas"*. And *"whilst PPI must be adaptable to local circumstances and objectives, the essential principles required to underpin its effectiveness may well be universal in their application"*.

This is a refreshing approach to the problem of defining PPI – and one that could put an end to those frustrating circular arguments.

06 | BITE-SIZE GUIDE TO PATIENT INSIGHT:

WRITING AN EFFECTIVE QUESTIONNAIRE

NHS England

Publications gateway reference: 07406

# Got questions? Get this.

## New bite-size guide offers handy tips on questionnaire design

You might think that writing questionnaires is a fairly basic skill for people involved in patient experience work. At the same time, we have probably all had experiences with questionnaires that were too long, or contained overcomplicated or irrelevant questions.

Writing a good questionnaire is harder than it seems, which is why this guide from NHS England is a welcome new addition to their *Bite-Size* series.

There won't be much in it to trouble academic researchers. But it offers a quick and handy reference point for any front line practitioners needing to put together a questionnaire while simultaneously handling complaints, writing committee reports, managing volunteers and keeping the boss happy.

Some of the advice may seem basic – for example "avoid using jargon". But as it progresses, the guide takes us into more interesting territory, covering "cognitive testing", "gratitude bias" and "bipolar" versus "unipolar" scales. That may sound as though the authors have ignored their own advice to avoid using jargon. But the terms are explained well, within a publication that – as with all Bite Size guides – is clear and concise.

The question of accessibility is touched on, with links through to further reading on the Accessible Information Standard, and consideration of how to hear from people who may find it hard to respond to a questionnaire – for example because of language barriers or sensory loss. Some of this is also covered in other publications within the Bite Size series.

A strength of the Bite Size guides is that they are short and to the point. In this case, the focus is all on the front end of survey work – the actual writing of questionnaires. It does not therefore cover the task of analysing the results once the completed forms come back in. A topic for the next guide perhaps?

In the meantime, if you need a questionnaire that patients – and your colleagues – can make sense of, this is the document to have ready to hand.

**The Inquiry into Hyponatraemia-related Deaths**

Report

January 2018

www.ihrdni.org
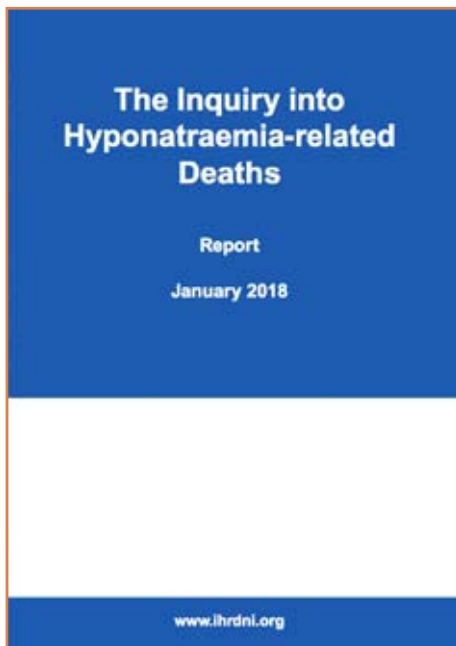
# More deaths. More learning.

## Unhappy parallels with previous inquiries

This long-awaited report deals with the deaths of five children in the care of health services in Northern Ireland. The children died in the late 1990's and early 2000's, and bereaved families have had to wait until now for a full and final account of what happened.
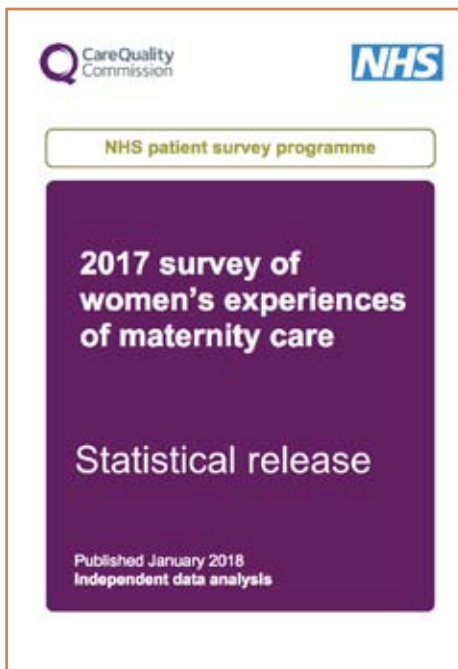
There are two common threads running through the families' experiences. The first is that their children died from hyponatraemia – an excessive dilution of sodium levels in the blood. According to the Inquiry report, this is a condition for which *"A diagnosis is made easily"*. It goes on to say that "*dilutional hyponatraemia should not happen in a hospital. It is a preventable hospital illness"*.

The second common thread is institutional denial of error, and appalling treatment of grieving relatives.

The Inquiry report describes *"an underlying institutionalised reluctance to admit major shortcomings"* and *"no acknowledgement of any of the very many failings in care"*. There was *"defensiveness, deceit and a strong inclination... to close ranks"*. Furthermore, *"clinicians did not admit to error for the obvious reasons of self-protection... this defensiveness amounted to concealment and deceit"*.

These statements are a clear, and dismaying, echo of similar statements in inquiry reports from Mid Staffs, Morecambe Bay and Southern Health. The "Recommendations" section of the report starts by saying that *"The lessons of these sad cases must be learnt because it cannot be assumed that such tragedy could not happen again"*. The Morecambe Bay investigation report carried an almost identical warning: *"It is vital that the lessons, now plain to see, are learnt... by other Trusts, which must not believe that 'it could not happen here'"*.

Mistakes can and do happen. There will be further avoidable deaths in NHS services. When they occur, the learning should not just be about improved practice and procedures. It should also be about how the NHS, as a healing organisation, learns to deal honestly and compassionately with bereaved relatives.

CareQuality Commission

NHS

NHS patient survey programme

**2017 survey of women's experiences of maternity care**

Statistical release

Published January 2018
Independent data analysis

# Better patient experience in Maternity Services

## Latest maternity patient survey from the CQC

The findings of the 2017 Maternity Services Survey have recently been published by the Care Quality Commission. Over 18,000 women responded to the survey and the good news is that there are *"small incremental improvements in results across almost every question that women were asked in the questionnaire"*, compared to the last survey in 2015.

Some of the key findings were that:

- More women in 2017 said they were offered the choice of giving birth in a midwife-led unit or birth centre than in 2013 (42% compared with 35%).

- In 2017, 77% of respondents said they were never left alone during labour or birth if they were worried, compared with 74% in 2013.

- Various aspects of postnatal care showed significant improvement, although the fact remains that experience of postnatal care remains generally less positive than other aspects of the maternity pathway.

- Women who said they did not see the same midwife throughout their antenatal care, and then did not see a consistent midwife during their postnatal care, felt their care was less compassionate than care for other women.

You can see the results of the survey for your local NHS Trust by visiting the CQC website. Or try the *Patient Experience in Trusts map*, for a quick view of the local maternity survey results, alongside all other key patient experience data in your area.
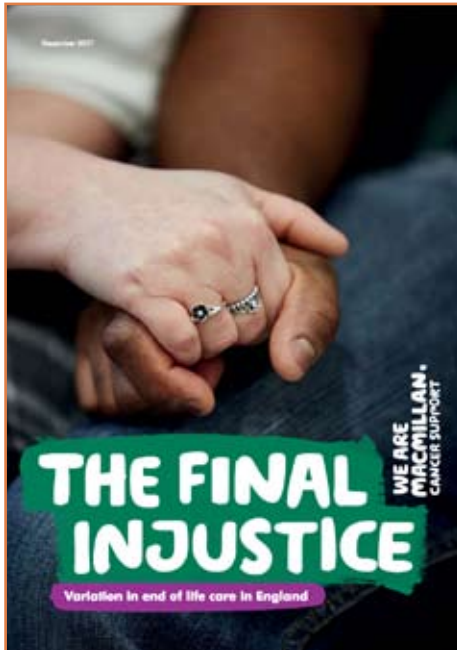
# Better experience at end of life...

## ... for patients and for "friends and family left behind"

"Patient experience" is not just about what happens to people who are unwell. It is also about how relatives and carers feel about the way that loved ones are being looked after. That is particularly true when it comes to end of life care.

As this report from Macmillan puts it, *"At a time when you are at the mercy of medicine, and of your own body, you can feel extremely disempowered and out of control. And, as a family member, you can feel that everything is happening to you and around you".*

The report notes that in July 2016, the Government made a 'National Commitment' to improve end of life care across England, regardless of geography, age, diagnosis, background or means.

But the commitment came with no extra funding. Implementation was left to local sustainability and transformation partnerships (STPs), but analysis of draft STP plans has shown that 41% had no mention or little detail of how end of life care would be improved.

The report authors state that *"there continues to be unacceptable geographic variation and inequality in the end of life care people with cancer receive in their dying months. While some people have choices around where they die, and the chance to spend time with the people who matter to them, others spend their final year in and out of A&E, and have little opportunity to access the care of their choosing".*

They go on to say that *"Each year in England, an estimated 48,000 people experience poor care in the final three months of their lives. And more than 12,500 cancer patients (10% of those who die in England each year) spend the last two days of their lives without adequate pain relief".*

The report makes a series of recommendations for how variations in end of life care could be better identified and addressed – not only for the sake of patients, but also because a good experience of end of life care can have *"a lasting and meaningful impact on friends and family left behind".*

# Ignoring the alarms

## PHSO condemns treatment of bereaved family

This hard-hitting report from the Parliamentary and Health Service Ombudsman concerns the death of a patient, Averil Hart, who died of anorexia nervosa, aged 19. There were *"multiple serious departures from the standards of care expected"*, and *"a long series of missed opportunities to recognise her deteriorating condition"*.

As in so many other cases, what happened next was that grieving relatives suffered the worst possible treatment at the hands of NHS organisations.

The PHSO examined the experience of Mr. Hart (Avril's father) through a prolonged period of enquiry and complaint. They found that *"most of the NHS organisations which dealt with Mr Hart's complaint failed to respond to his concerns in a sensitive, transparent and helpful way"*.

Responses to requests for information *"were delayed and appeared evasive, and information he requested was often not provided"*. Responses to complaints *"were equally unsatisfactory, and often appeared defensive or protective of the organisation concerned"*. There was *"a consistent picture of unhelpfulness, lack of transparency, individual defensiveness and organisational self-protection"*.

The report is entitled "How NHS eating disorder services are failing patients". But this is not just about eating disorder services. Multiple organisations and services were complicit in the poor treatment of the family following Avril's death. The PHSO says this:

- "The Cambridgeshire and Peterborough Trust's handling of Mr Hart's complaint was so poor that it was maladministration."
- "The GP practice's complaint handling was so poor that it was maladministration."
- "The Norwich Acute Trust's complaint handling was so poor that it was maladministration."
- "NHS England's approach... was so poor that it was maladministration."

The report finishes with this:
*"The death of Averil Hart was an avoidable tragedy. Every NHS organisation involved in her care missed significant opportunities to prevent the tragedy unfolding at every stage of her illness from August 2012 to her death on 15 December 2012. The subsequent responses to Averil's family were inadequate and served only to compound their distress. The NHS must learn from these events, for the sake of future patients."*

# Patient experience, public satisfaction and politics

## NHS still treasured, but public dissatisfaction grows

Reports on "patient experience" usually focus on people's experience of specific NHS services. This briefing, using data from the British Social Attitudes survey, looks at general public satisfaction with the NHS as a whole. As the authors state, *"Polling on public attitudes is different, because people tend to focus on wider issues as well as their experience of care when responding. Not everyone responding to a public poll will have used the NHS recently"*.

So how satisfied are the general public with our health service? The good news is that *"the NHS remains a treasured national institution that is a key part of the British national identity. The public is unwavering in its support for the underlying principles of the NHS and consistently prioritises the health service for extra government funding"*.

The bad news is that *"public dissatisfaction with the NHS grew to 29% in 2017… the highest level of dissatisfaction with the NHS since 2007"*. Further, *"Dissatisfaction with the NHS has risen rapidly over the past three years: between 2014 and 2017, the level of dissatisfaction almost doubled"*.

The top two reasons for satisfaction were "quality of care" and "free at the point of use". The top two reasons for dissatisfaction were "not enough staff" and "takes too long to get an appointment". There is an interesting mix here of opinions that may stem from patient experience but which could also reflect political viewpoints.

The question of political viewpoints is important. The conclusion to the briefing states that *"With an increase over the last few years in the proportion of survey respondents reporting lack of funding as a reason for their dissatisfaction, it seems the public is increasingly aware of the reality of funding pressures that the NHS has experienced"*. It finishes by saying that *"With equally small increases in funding planned over the next few years and NHS performance on key headline measures worsening, it is hard to see the public's satisfaction with the NHS improving in the near future"*.

# Patient surveys: read the small print

## Why patients give perfect ratings accompanied by negative comments

A common feature of patient surveys is some form of ratings system to indicate levels of satisfaction. Patients may be asked to give one to five stars for aspects of the service they have experienced, or to score from 1 ("Very Poor") to 10 ("Excellent").

Patient experience staff are always pleased to see top scores against survey questions. But this study, published in the Patient Experience Journal, suggests that the top scoring responses may merit a closer look.

The authors analysed almost two years of in-patient survey data from a large hospital system in the US, and found, puzzlingly, that *"a significant percentage of patients provide perfect domain scores only to follow up with negative comments"*. They wanted to investigate this apparent contradiction.

One finding was that patients sometimes use free text comment boxes on a survey form to raise issues that are not addressed by the actual survey questions. In one example, the survey asked about matters such as controlling pain or meeting emotional needs. But the patients, via their free text comments wanted to raise issues such as support staff and understanding of medications.

A second consideration is that *"patients who are highly loyal to an organization may not want to decrease their ratings, based on an understanding that ratings are important to the organization"*. Giving high ratings while airing problems via the comment boxes may enable patients to express loyalty to the organisation, while simultaneously (and as a kind of quiet aside) suggesting room for improvement.

A further point is that *"a patient may see a health domain as being predominantly great, but spoiled by 'one bad apple'"*. For example, a survey question on "nurses" in general may be rated as excellent, while the comment box reveals a problem with one nurse in particular.

The study contains plenty more interesting detail. But its overall message seems to be that if that if you get a five star survey response, don't rest on your laurels. For real learning, read the small print.

# 2018 Experience of Care week

*23 – 27 April*



Co-ordinated by NHS England and NHS Improvement, the week aims to promote and celebrate all aspects of patient experience, with webinars, Twitter chats, a *We Communities blog*, local events, and social media activity.

If you're taking part, you can *download free graphics and resources from here*. And if you're tweeting, remember to use *#ExpofCare*.

## FFT debate gathers steam

NHS England's *announcement of a review of the Friends and Family Test* has prompted considerable online debate. Much of it revolves around a *BMJ article*, questioning whether the FFT should be mandatory.

The article quickly garnered as many *reader responses* as any BMJ editorial piece in the last 12 months – most of them thoughtful and well written.

The authors have followed up with *a further piece*, referring to FFT as a "zombie measure".

What do you think? NHS England is working out the terms and timetable for the review, but has invited anyone with an interest to get in touch at *england.insight-queries@nhs.net*

# What matters to you day

*6 June*

Across healthcare, Wednesday 6 June is what matters to you day, encouraging health and care practitioners to change their conversations with people from 'what's the matter with you?' to 'what matters to you?'. This is an international campaign: see how it's been running in Scotland at *www.whatmatterstoyou.scot*. NHS England is getting the English campaign up and running – for more info please contact *Jayne.beecham@nhs.net* or *jonathan.berry2@nhs.net*.

Join the Twitter conversation at *#WMTY2018*.



**NHS England** is promoting a series of courses for patients, public and professionals on topics relating to patient experience and patient public involvement. Examples include:

- Empowering citizens and patients to participate

- NHS England Patient and Public Voice (PPV) Partners' Induction Webinars

- Developing patient and public participation skills and understanding

- Understanding the value of engagement

- Measuring the impact of engagement

- Planning your engagement activities

*Further details can be found here*

# The Patient Experience Library

Our ground-breaking initiative has collated and catalogued the whole of the UK's collective intelligence on patient experience. We can offer access to over 40,000 documents on patient experience and patient/public involvement, from government bodies, Healthwatch, think tanks and health charities.

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